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Stories of MDM: Helping Patients and Clinicians Manage Uncertainty During Clinical Care
Mary C. Politi, PhD

I once counseled a patient who was struggling to understand her breast surgeon's words:
"Studies show *some* benefit in *some* women..."

The surgeon's statement was accurate. But they didn't answer the kinds of questions my patient had. Questions like: Would she be one of the women who benefitted from the proposed treatment plan? What does "some" benefit even mean?

Those questions are difficult because they are grounded in uncertainty. Although we can estimate odds overall in the population, we cannot know what will happen to any individual patient. It is always hard to sit with uncertainty. The challenge for my patient, and for every patient, was moving forward despite the unknowns about one's health.

As a psychologist working at a cancer center, my job was to support patients through the emotionally-intense process of receiving a cancer diagnosis or potential diagnosis. I often found myself sitting with patients and researching literature on possible outcomes. I spent a great deal of my time helping patients understand the research and balance their options in cases where there was no clear best choice.

Making sense of uncertainty was further complicated by a barrage of emotions patients felt after hearing the word "cancer." Surgeons often asked them "do you have any questions?" after going through a litany of details about treatment options and the associated uncertainty about outcomes and side effects. Patients would just shake their head no.

It's not that my patients didn't have questions. It's just that the questions would come later, after they had time to process their diagnosis and sit with their accompanying emotions. Only then could they think about risk, benefit, and potential side effects of treatment options presented to them. But providers' busy schedules and patients' understandable desire to start treatment as quickly as possible usually made follow-up opportunities to ask questions about uncertainty challenging.

Although most providers today recognize the importance of transparent communication about uncertainty and treatment options, many providers at the time trained before true patient-centered care and shared decision making (SDM) communication were taught in medical school. And even among those who supported patient-centered care, real patient engagement was difficult to achieve without commitment, motivation, and a more complete understanding of the patient experience.

The patients that I worked with helped me to realize that a key part of understanding the patient experience involves gaining insight into how they interpret and react to uncertainty. It also became clear that managing uncertainty was difficult for both patients and providers. Both wanted to

feel confident in a treatment plan with known outcomes; talking about the uncertainty inherent in most medical decisions was not easy.

As I worked with patients to make sense of their illness and the uncertainty associated with it, I began researching how providers could guide patients through this process systematically and with purpose. Working with Paul Han and Nananda Col, I explored best practices for managing uncertainty during health care visits. Our early work revealed a lack of consensus regarding best practices and, more than anything, underscored the need for additional studies to investigate fundamental questions about how people process, interpret, and respond to various types of uncertainty inherent in clinical decisions (Politi, Han and Col 2007). One consistent recommendation did emerge from the existing literature, though: to better support patients' decisions, clinicians should, at the very least, acknowledge uncertainty, clarify its sources, and communicate to patients as partners to help them through the emotionally laden process of grappling with unknowns.

As I continued this research, it became clear that this was easier said than done. Colleagues and I explored how physicians' reactions to uncertainty influenced their comfort with and willingness to engage in SDM (Politi & Legare, 2010). Younger clinicians and those with fewer years of formal education were more uncomfortable disclosing uncertainty to patients, perhaps because they did not want to appear as if their inexperience was the source of uncertainty. Female clinicians reported more anxiety from uncertainty, but this did not impact their willingness to disclose uncertainty to patients. In fact, it might be that clinicians who can relate to patients' discomfort with uncertainty are better equipped to help patients cope with it by providing information in a supportive, patient-centered way.

Many colleagues, clinicians and SDM researchers alike, might find it surprising that acknowledging uncertainty can initially lead to lower patient satisfaction. But this is obvious to patients. Everyone wishes there were a magic pill or treatment that is guaranteed to work with no side effects or tradeoffs. Talking about the realities of medicine—that we unfortunately can't have a perfect, treatment with certain benefits and no risks—can complicate an already stressful diagnosis for patients.

However, when providers consistently acknowledge uncertainty, model how to cope with it, and incorporate it into the decision making process and development of a treatment plan, they can mitigate some of the stressful effects of uncertainty. A later study highlighted this by showing that clinicians who engaged in patient-centered behaviors positively impacted the SDM process, even when patients found it difficult to hear that there might not be one best option for their care (Politi, Clark, Ombao, Dizon & Elwyn 2011).

Although patients' discomfort with uncertainty can be mitigated through SDM processes, clinicians continue to struggle to engage in these conversations. As a result, my recent focus has been on training and educating providers in SDM communication. Challenges remain among both patients and clinicians. Many of my patients in clinical and research settings express a desire to engage in SDM, but they do not know exactly how to balance this with their own style of communication. From a clinician's perspective, many clinicians believe they are already practicing SDM. In fact, however, they may be engaging in components of SDM without fully incorporating patients to the extent that patients desire (Politi, Dizon, Frosch, Kuzemchak, & Stiggelbout, 2013).

Anxious questions like those weighing on my breast cancer patient—will I be one of the patients who benefit? What does this uncertainty mean for me, here, now, sitting in this room?—will always

echo in the heads of patients and providers alike. They're the inevitable result of applying population-level outcomes and statistics to an individual's health.

My clinical and research experiences have shown me just how much both clinicians and patients need assistance coming to terms with this uncertainty and incorporating it into decisions. In particular, I have seen how patients need more context and support when faced with vague statements such as "some benefit," and how clinicians need guidance and skills to better present uncertainty to patients. Acknowledging uncertainty and collaborating with patients through the unknowns of medical care is not easy, but can have long-lasting benefits for both patient care and the patient-clinician relationship. We have a long way to go, but I am encouraged by both the patient- and clinician-led movements to bring patient-centered care and patient and family engagement into the management of uncertain decisions.

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